ABSTRACT

Health Heritage (HH) a web-based family health history tool Wendy F. Cohn, PhD

Objective: Health Heritage (HH) is a web-based family health history tool developed to assist individuals to collect and maintain their family health history information and primary care providers to apply evidence-based algorithms to assess risk for 89 hereditary conditions in 5 areas. Both individuals and their providers are given recommendations for prevention and treatment tailored to individual health risk levels. After HH was developed, we conducted a pilot test to evaluate: (1) completeness and accuracy of the family history information; (2) completeness and accuracy of the risk assessments; and (3) satisfaction with the HH website.

Methods: A web-based group used HH to record their family health history (HH group) and evaluate their risks for the 89 HH conditions. The Usual Care group (UC group) had their family health history abstracted from their existing medical record reflecting care received from their regular primary care provider, and then a genetic specialty team assessed their health risks for the same 89 HH conditions. Both groups completed a phone interview with a genetic counselor (GC) to provide "the gold standard" family history criterion for comparison. The HH group also completed a satisfaction questionnaire.

Results: (1) HH was an improvement over UC in all areas of family health history collection assessed in this pilot study. (2) Compared to the GC, HH performed at least as well in identifying relationships, ages, and conditions, but not as well at capturing the total number of relatives. (3) HH participants were satisfied with the quality, confidentiality, and security provided by HH.